

## **PRESENT**

Ms. Betsy Abramson, Dr. Patricia Flatley Brennan, Dr. Rich Brown (for Dr. Smith), Ms. Nancy Davis, Dr. Jay Gold, Ms. Dianne Greenley, Ms. Catherine Hansen (Chair), Ms. Chrisann Lemery, Ms. Susan Manning, Ms. Kathy Johnson, Mr. Greg Schneider, Ms. Amy Wergin, Ms. Alison Bergum, Dr. Larry Hanrahan, Ms. Stacia Jankowski, Ms. Audrey Nohel, Ms. Judith Nugent

## **ABSENT**

Mr. Peter Daly, Ms. Patricia Finder-Stone, Mr. Ken Germanson, Ms. Sadhna Morato-Lindvall, Mr. Richard Perry, Mr. Paul Harris, Mr. Matthew Miszewski, Mr. Raghu Ramakrishnan, Dr. Paul Smith, Dr. Seth Foldy, Ms. Donna Friedsam, Ms. Susan Wood

### **I. INTRODUCTIONS BY PARTICIPANTS**

At the request of the chair, workgroup members, resources, and staff introduced themselves.

### **II. APPROVAL OF MINUTES**

Minutes from the June 23, 2006 meeting of the workgroup were approved as submitted.

### **III. WORKPLAN ADDITIONS**

Ms. Bergum presented items for the group to consider adding to its workplan for future discussion. The following items will be added in support of the charge to *identify outcomes/options that meet consumer expectations/prepare consumers to manage their own care and advocate for themselves*: (1) an education campaign aimed at increasing consumer understanding and acceptance of electronic health records (EHR) and health information exchange (HIE), including personal health records (PHR); and (2) a discussion of the potential and limits of electronic patient-provider communication. It was suggested that a representative of Group Health Cooperative (GHC) be invited to share the capabilities of MyChart.com as an example of such e-communication.

The group agreed to review the types of data the Patient Care workgroup selected as high priorities for inclusion in HIE over the next five years to identify potential privacy concerns and ensure that patient-friendly elements are incorporated. Prior to finalizing its recommendations, the group will also: (1) discuss potential roles for consumers in the governance of HIE; (2) consider the necessity of a statement regarding potential consumer-borne costs related to HIE; and (3) revisit all draft recommendations.

### **IV. REVIEW CONSUMER INTERESTS WORKGROUP CHARGES/TIMELINE**

Ms. Bergum reviewed the proposed timeline for the charges outlined in the Consumer Interests workgroup charter, noting that draft recommendations have been added to the document. Workgroup members suggested adding sexual abuse and domestic violence to the discussion of the treatment of health information with special protections and noted the importance of considering possible uses of health information throughout this discussion.

### **V. HEALTH INFORMATION SECURITY AND PRIVACY (HISPC) UPDATE**

Ms. Bergum reported that the project team participated in a Research Triangle Institute (RTI) (grantor) training and is moving forward on the second project deliverable: capturing variations in

organizational policies and practices regarding the release and exchange of data. Staff will be hired at UW and DHFS and a variations workgroup will be formed to support this effort. She noted that Minnesota is also funded under HISPC; plans are underway to discuss cross-border issues.

## **VI. APPROACHES TO SENSITIVE HEALTH INFORMATION IN HIE INITIATIVES**

Ms. Bergum reported that many states and Regional Health Information Exchange Organizations (RHIOs) indicate only that they adhere to HIPAA regulations and applicable state laws regarding sensitive health information. In its Health e-Connections Roadmap, Arizona outlined five options for handling this information. Maine's Consumer Stakeholder Committee chose to recommend specific safeguards for this information but did not specify the nature of these safeguards.

## **VII. CURRENT TREATMENT OF SENSITIVE HEALTH INFORMATION UNDER HIPAA AND WISCONSIN LAW**

Ms. Manning provided the group with an overview of HIPAA and Wisconsin law. She reported that these laws require patient authorization to disclose patient health care records but by state or federal exemption, other statutory authority, or in other limited areas, records can be disclosed without patient authorization. Generally, Wisconsin law controls as it is often more protective than HIPAA. Ms. Manning's slides are online at:

<http://ehealthboard.dhfs.wisconsin.gov/workgroups/consumer/ci-materials.asp>.

## **VIII. DISCUSSION: PRELIMINARY RECOMMENDATIONS FOR TREATMENT OF SENSITIVE HEALTH INFORMATION**

Ms. Hansen asked the group to work through the decision guide, keeping Ms. Bergum and Ms. Manning's presentations in mind and keeping their "patient/consumer hats" on. Some members of the group supported the inclusion of sensitive information, asserting that *not* having such information would be detrimental to patient care. Others stated that their position depends on the *types* of information exchanged; the mental health community, for example, opposes the transfer of therapy notes but generally accepts sharing medication lists. Some individuals expressed concern that inclusion of this information may discourage patients from seeking needed care.

The group agreed that these decisions depend heavily on: (1) who has *access* to the information included in exchanges; (2) a patient/consumer's ability to influence (or limit) access; and (3) whether an individual is receiving routine or emergency care. Moreover, patients must be made aware of the risks and benefits of exclusion.

## **IX. CONSUMER CARE-SEEKING AND SENSITIVE HEALTH INFORMATION**

Dr. Brown presented a proposal to study how Wisconsin's e-health effort might further discourage patients from seeking needed care. The group will discuss this further via e-mail.

## **X. CONSUMER LISTENING SESSION UPDATE**

Ms. Bergum reported that the Consumer Listening Session is scheduled for September 12 in Oconomowoc from 1:00–4:00, preceded by a workgroup meeting at 12:00. She encouraged group members to attend in person and e-mail her individuals and organizations to be invited.

## **XI. MEETING EVALUATION**

To save time, the group was encouraged to e-mail Ms. Bergum with comments or concerns.

**Next Meeting:** July 28, 2006